



**ABSTRACT** 



9630: BRFSS State-Added Questions: Leveraging an Existing Surveillance System to Monitor Prevalence and Health Indictors for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

**BACKGROUND:** ME/CFS is a debilitating, multi-system, long-term illness. According to 2015 Institute of Medicine report, about 836,000 to 2.5 million Americans suffer from ME/CFS. Although cross-sectional and longitudinal studies have reported prevalence estimates, no surveillance system periodically monitors prevalence of ME/CFS and its associated health indicators in the United States. One cost-effective way to establish a surveillance system for ME/CFS is to integrate questions into existing systems.

**METHODS:** In 2014, previously validated questions on self-reported ME/CFS diagnosis were included as state-added questions to Behavioral Risk Factor Surveillance System (BRFSS) by five states (Alabama, Connecticut, Kansas, Nebraska, and North Carolina). The two questions captured the lifetime and current prevalence of ME/CFS. Alabama, Kansas, and North Carolina, continued to include the questions for 2016 BRFSS survey.

**RESULTS:** A total of 54,695 respondents answered the questions. The respondents had a mean age of 54.8 (± 18.2) years and mean body mass index of 28.2 (± 6.2) kg/m<sup>2</sup>; 42.3% were female, 82.8% white/non-Hispanic, 54.7% married, 62.4% with some college education. About 1.6% reported previously receiving ME/CFS diagnosis. Of these (n=668), 71.4% still have ME/CFS and they were more likely to be female (81.6%), white/non-Hispanic (85.8%), aged 45 years or older (81.1%), educated (59.5%), overweight or obese (71.8%), and had good income (only 25.0% with annual household income < \$10,000). For functional disability, 78.8% reported having difficulty in one of these areas: 1) concentrating, remembering, or making decision; 2) walking or climbing stairs; 3) dressing or bathing; and 4) doing errands alone. Among 11 health conditions reported in BRFSS core questions, 83.4 % of respondents with current ME/CFS had two or more comorbid conditions. The majority had insurance (88.5%) and one or more healthcare providers (91.2%). However, 35.9% had forgone needed healthcare because of cost and 15.5% had not received routine check-ups within past two years.

**CONCLUSIONS:** Information from state-added ME/CFS along with the BRFSS core questions (e.g., health-related risks, chronic conditions, and healthcare access and utilization) is a novel way to gain insight on ME/CFS without a separate and costly surveillance system. Our prevalence estimates of ME/CFS (lifetime 1.6%; current 1.2%) were similar to Canadian Community Health Survey 2005, 2010, and 2014 data. Data from this study approximate other studies and the literature in terms of ME/CFS health indicators and demographics. Expanding BRFSS with supplemental questions on ME/CFS can provide important information on risk factors and outcomes that may not be available from other sources.

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